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GOVERNOR'S COUNCIL FOR PEOPLE WITH DISABILITIES
ANNUAL CONFERENCE

"INVEST IN PEOPLE: SHARE IN THE PROFITS"

PLENARY SESSION

"HEALTHCARE REFORM: A HIGH STAKES GAME"

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>> STEVE TILDEN: Thank you, Suellen. You got me for two days. I wanted to take this opportunity to talk about healthcare. That's what this panel is about today. And I stumbled upon an article in Newsweek a few weeks ago that you may have seen. And it's about -- it surveys a book that was just published in October by a T.R. Reid. It's called "The Healing of America: A Global Quest for Better, Cheaper and Fairer Healthcare." I have it if you want to talk to me about it later, I'll show it to you.

But I've summarized some of the points in it. And it's kind of a macroview of healthcare in the other industrialized countries of the world, the top 10 or so industrialized, rich countries, and how they deal with healthcare compared to us, to the United States.

So that being said, I've got some things that I want to summarize. It's not exactly like a book report, but it tells about factually.

T.R. Reid is a well-traveled author. He's written other books. And he's spoken on NPR and been around a lot and he has researched these countries. It's nonfiction. It's true. There's lots of footnotes in the book. So this is a factual presentation of how the top industrialized countries, the rich countries in the world, deal with health care.

We continue to hear about the bad, socialized healthcare system of Canada. But my experience -- and as is T.R. Reid's experience -- are a bit understated by nature. Canadians don't go around chanting "we are number one" and asking God to bless them only. However, there are two areas where Canadians feel they are better than the United States: Hockey.

[Laughter]

And healthcare. So I probably give them number one in those two things.

Canadians point out that Canada provides coverage for everybody, usually with no copay and no deductible, while the United States lets some 700,000 people go bankrupt due to medical bills each year while the number of medical bankruptcies in Canada is precisely zero.

While Canada does not provide free and prompt care to all -- I'm sorry.

While Canada does provide free and prompt care to all for acute emergency medical conditions, for nonemergency or nonlife-threatening commissioned cases, people do have a waiting list before they receive some care. But it's still free. They don't seem to mind too much as long as the poor people in Canada and the rich have to wait about the same amount of time.

In his research, author T.R. Reid found that Canadians,

like all other industrialized countries except the United States, has a national ethic of healthcare that medicine is not a commodity to be sold to the highest bidder but a right that must be distributed equitably to one and all.

Canadians have built a health care system that fits their character: Ferocity, egalitarian, but at the same time thrifty.

Princeton Professor Rhinehart says "the fundamental truth about healthcare in every country is that national values, national character determine how each system works." National values, national character determines how each system works.

The design of any country's healthcare systems involves political, medical and economic decisions; but the primary issue for any healthcare system is a moral question: Should a rich society provide healthcare to everyone who needs it? If yes, then it will build a system like the ones in Britain, Germany, Canada, France and Japan where everyone is covered.

Without the moral commitment, you end up with a system like in the United States.

In Britain, Spain and Italy, the basic rule of medicine is that people never get a doctor's bill. Healthcare, like building roads or putting out fires, is funded through general taxation.

However, in France, patients are expected to make cash

payments for any encounter with the health care system, even though the insurance plan will reimburse most of the copay within a week or so. The French have decided that people should be reminded on every visit that health care costs money, even if it's the insurance company's money. In other words, these other industrialized rich countries do it different ways, but they all do it.

In Germany and Austria, health insurance pays -- this is one of the areas that there's some differences. This is funny. In Germany and Austria, health insurance pays for a week at a spa if a doctor prescribes it to deal with stress.

[Laughter]

But in Britain, doctors laugh at the very thought of it. So they have different ways. But one could argue that stress, take Prozac or whatever it might be, costs money, but a week at a spa might really help people. So different countries have different systems. That's the point there. But it is humorous.

The U.S., the United States, the world's richest and most powerful nation, is the only advanced country that has never made a commitment to provide medical care to everyone who needs it. The consequences are that about 22,000 Americans die each year of treatable diseases because they lack insurance and can't afford a doctor.

Additionally, the U.S. is the only developed country where medical bankruptcies can happen. And as I mentioned earlier, approximately 700,000 medically-related bankruptcies happen. They don't happen in any of these other countries.

A French physician, Dr. Valory Newman, explained it this way: "You Americans say that everyone is equal. But this is not so. Some people are beautiful. Some aren't. Some are brilliant. Some aren't. But when we get sick, then, yes, everybody, all people are equal. That is something that we French people can deal with on an equal basis. The French people feel like that unlike beauty and brains, all people should equally have access to care when it comes to life and death. All other industrialized countries have the same principle", as I just explained, the French with slightly different explanations.

For example, in Switzerland, the underlying rationale is the concept of solidarity, a sense of community, equal treatment; and despite all our differences, we're all in this together. The formula of healthcare for everybody, paid for by everybody, is so obvious and cost-effective people in Europe, Canada and eastern Asian countries do not understand why the clever Americans have not figured it out.

Note: Total health care costs for the industrialized

countries average, except the United States, where they cover everybody, averages slightly 10% of GDP while the total healthcare costs of the United States is about 16%. Yet the live birth rate and the higher death rates and all the other parameters are worse in the United States where we pay 16% overall when the average is for the other countries that pay less than 10% where they cover everybody. Interesting.

I found a quote from Winston Churchill from World War II. He may be right. I hope he's right. But Winston Churchill once said that, "Americans will do the right thing, after they've tried everything else."

[Laughter]

Well, we've been trying everything else. I hope we do the right thing now.

Some nations, Britain, Spain, Italy and New Zealand, among others, have decided that providing healthcare is a job for government, just like building roads or putting out fires. In those countries, government owns the hospitals, employs many or most of the doctors and pays the bills. This seems like what Americans think of as socialized medicine. However, many rich democracies, like Germany and France and Switzerland and the Netherlands and Japan provide universal coverage with private doctors, private hospitals and mainly private insurance plans.

This isn't Socialism.

Unlike Americans, who switch to government-run insurance Medicare at age 65, that's government-run insurance at age 65, Germans stick with the same system, private insurance, from cradle to grave. And they started in the 1890s with national healthcare, by the way, under Bismarck.

Japan has more for-profit hospitals than the United States does and far fewer doctors on the government payroll than we do. This is universal coverage in Germany and Japan, but it's not Socialism.

Some countries, Canada, Taiwan, Australia, have a blended system, with private sector doctors and hospitals, but a government payment system.

The Canadian model, private provider but public insurance to pay them, is a system President Lyndon Johnson copied when Medicare was created in 1965. The difference is that Canada, Taiwan and Australia provide the public insurance for everybody while the U.S. restricts it to seniors and the disabled.

In the current debate on healthcare, many warn that universal coverage will inevitably lead to rationing of healthcare. The basic fact is that the U.S. already rations healthcare. Every country rations healthcare, because no system can afford to pay for everything. The distinction is the way

rationing happens.

In the other developed democracies, there's a basic floor of coverage that everybody equally is entitled to. That is why nobody dies in those nations for lack of care. And nobody goes bankrupt due to medical costs. There are, however, limits on which procedures and which medications the system will pay for. That is where the rationing kicks in.

In the United States, in contrast, some people have access to just about everything doctors and hospitals can provide. But others can't even get in the door unless they go to the highly expensive emergency room. That amounts to rationing care by wealth, which seems natural to Americans; but to the rest of the developed world, it looks immoral.

I want to give this outline of this factual book as a macroview before we get into our health care discussions to give us some more perspective, because we don't hear this with all the ads and stuff on TV from both sides. Most of us don't really understand what the rest of the industrialized, wealthy countries do and how they've dealt with this in the past.

I think the United States is big enough to take and not think that we are absolutely the only way to do things. Other people have developed other ways of doing things that work quite well. This book is dedicated, by the way, to President Dwight

D. Eisenhower, a Republican. The book is dedicated to him. Because when he was leading the allies in fighting World War II and he got into Germany with his troops, what did he find? He found interstates. He found Audubons. And they got the tanks and they could drive all over Germany and they took Hitler very quickly.

When President Eisenhower, Republican, became President in 1952, one of the things he said is that the United States had two-lane highways all over the country, mishmash. We didn't have interstates. And he took this idea from Germany, the Audubons that worked and was efficient, and he said -- well, he didn't worry about Socialism to say we needed interstates, but he said this is in the best interest of the country. But many people fought interstates because all the little two-lane roads went through towns and things like that. And he had to get approval. But they built the interstate system, which has been a savior for the United States. We took an idea from another country that worked and because it worked and we've developed it here and perfected it.

So I think we need to be more open-minded. And the more people that can understand or that we could have understand that we need to look at things more broadly, and that's basically all I wanted to say as a precursor to the panel today. Thank you.

[Applause.]

>> STEVE VIEHWEG: Thank you, Steve. So now we'll begin the next presentation. Our panel members can come on up, please. My name is Steve Viehweg. I'm a member of the Board. My role is to be the moderator of this group. If they become unruly, I'll be in charge of keeping them under control.

While they're all coming up here, before we introduce our speaker, I wanted to share that this topic is really complicated. And it's important for us to learn about all the correct information that we have so we could be the best advocates about this topic of healthcare. But I noticed yesterday that our agenda had some nice health topics on it, including yoga. How many went to yoga yesterday? Was that awesome? I was so relaxed by the time I got to that fabulous party last night. How many went to the party? I didn't hear you.

[CHEERS AND APPLAUSE]

Wasn't that fun? So I thought to get your brains going this morning, we could just relive one of our favorite functions last night and everybody could do the YMCA, right? So let's do Y-M-C-A? (humming the music).

Y-M-C-A.

Y-M-C-A.

The interpreter didn't do that.

Okay. Are your brains gone now? That was a fun party last night. That was great. It was good to see people having a good time. That's a healthy thing to do.

So today, this morning, we're going to spend some time listening about healthcare. And we have a very nationally known, smart person here to help us understand about healthcare reform; and after that, we have an esteemed panel of Indiana experts who are going to help us ask questions and have accurate information, because what we all want to leave here with today is some good, accurate information and to know where to get more information.

So first we're going to hear from Liz Savage. She's here from Washington, D.C. with the latest information on the debate, and then afterwards we'll hear from our Indiana healthcare advocates. So let me introduce Liz to you. She's the Director of Health and Housing Policy for Disability Policy Collaboration, which seeks to influence national policy for people with intellectual disabilities, cerebral palsy and related disabilities and their families. Liz is a recognized leader in the disability community. She cochairs the Consortium for Disability Health and Housing Taskforces. Her healthcare policy works focuses on Medicare and Medicaid and the impact of

changes on people with disabilities.

Liz is considered to be the "Mother of the ADA," for her efforts in the late '80s in coordinating a coalition of 75 disability Civil Rights, religious and civic organizations, all working towards the passage of the ADA.

During the Clinton Administration, she was appointed Special Assistant Attorney General for Civil Rights and directed the Justice Department's enforcement of the Americans with Disabilities Act. She's the first person with a disability to hold so high a position within the Department of Justice.

Liz is the recipient of several awards for her disability rights work, including the President's Committee on the Employment of People with Disabilities' Distinguished Service Award and the National Council on Independent Living's Individual Achievement Award.

So we are delighted to have her here this morning with us to talk about healthcare reform. She is going to stay seated and talk with us, and I'm going to be in charge -- this is a partnership -- of moving the slides. So we are going to do our best so you can enjoy the work together on the PowerPoint. But she's not going to do that, she's making me do that. Yeah, so it's a partnership. So give Liz a good Hoosier welcome.

[Applause.]

>> LIZ SAVAGE: Thank you very much. Good morning. Can you hear me?

>> AUDIENCE: Yes.

>> LIZ SAVAGE: You can hear me? Thank you very much, Steve, for that very generous introduction, way too generous. And for also being my partner on the slides. I'm legally blind. I have degenerative myopia. So I'm getting assistance on doing a PowerPoint is what the ADA calls an example of a no cost to reasonable accommodation, which many of us talked about for years.

>> Steve: I'm not paid?

>> LIZ SAVAGE: Not from me.

And on the slides in advance, my apologies. A couple of them are duplicates. I had to do a presentation that was shorter than this at the AARP's national convention last week in Pittsburgh, and my assistant messed them up. So my apologies because a couple of them are duplicates. But Steve is so proficient that he'll move along with my voice.

We're at a very exciting time in Washington with respect to healthcare reform. Many Presidents, as you may know, have tried to enact broad-based comprehensive health reform in this country, starting, I believe, with Teddy Roosevelt. Lyndon Johnson made significant progress with passage of Medicare and

Medicaid in 1965. And that was the last time that there was a successful enactment of major health reform law. President Clinton, as you may recall, tried but failed, unfortunately, in the mid '90s. So this is what a really historic moment. And we call it a once-in-a-generation opportunity. We really think that we're on the brink of passing something that will make a significant difference in the lives of all Americans.

Remember that healthcare affects 1/6 of our economy. So it is significant for everyone. But it will also make a significant difference in the lives of people with disabilities and their families, which is what I really want to talk about for most of my presentation today.

But before I do so, I want to put it in a larger context. Steve started that with a conversation about T.R. Reid's book, which I commend to you. I had the privilege of hearing him talk about his book in Washington. He's really a terrific writer. He used to write for the Washington Post, and he's a terrific speaker. And I'm sure the book is really wonderful based upon what I heard him say.

>> What's the title?

>> LIZ SAVAGE: What's the title? Healing America? We'll figure that out and during the panel we'll tell you.

But what I want to talk about to begin with is really the

purpose and the context of the healthcare reform that Congress is considering now and that President Obama wants to pass. As you know, healthcare reform is the President's highest domestic priority for this year, and therefore it's the Congress's highest priority.

I will say at the beginning because people always start with this question: Well, is this going to pass? And my firm belief -- which is not just me, but it's the consensus of most people in Washington -- is that something will pass. It might not pass by the end of December, this year, but it will pass by early next year. And it may not be perfect, but it's going to be a significant improvement.

So what's its intended purpose? Well, first is to cover the uninsured. There are almost 50 million people in this country, Americans, who have no health insurance whatsoever. And as Steve mentioned, they end up in emergency rooms across the country, and that is very, very costly to the system. All of us end up paying for that in higher premiums. It's estimated that every individual with employer-based coverage pays an extra thousand dollars in higher premiums to cover uncompensated care for people who don't have insurance.

In addition, as Steve mentioned, there are millions of people who are underinsured, who don't have adequate coverage to

meet their needs. And it's the hope and intention of this health reform to bring those individuals more adequate coverage to meet their needs.

Additionally, and this is very important, the purpose is to decrease the skyrocketing healthcare costs that are the norm in this country and are only increasing year by year. Rising healthcare costs are really not sustainable for the economy we're in or that we will be in in the future, because think about it, our society is aging. More people are living longer; therefore, healthcare costs, by necessity, are going to go up, so we have to do something to really decrease healthcare costs but provide people with quality care and access to quality care. So how do we do that?

Well, the third point and purpose of the reform effort is to really shift the model or the paradigm for how we view healthcare in this country from an emphasis on sickness to one on wellness. Now you go to the doctor from when you're sick, you don't necessarily go -- or most people don't go for preventative services. So there are a lot of provisions in the bills, both in the House and Senate, for prevention and for chronic disease management to prevent disabilities or diseases like diabetes from getting worse and costing the system more.

And the fourth purpose, which is really critical to

achieving all of the others, the previous three, is to increasing the number of primary care providers, specifically physicians, in this country, because there's an incredible shortage, especially in rural areas. So there are a lot of incentives in the bills for increasing physicians.

So keep in mind those are the overall purposes of the reform efforts.

Now, this has been a rather complex effort. There are three committees in the House that worked on this that have jurisdiction and two committees in the Senate. The House merged its three bills, and recently, about a week and a half ago passed a bill by a very slim margin 220-215 votes. About 39 Democrats opposed it. About 15 of those 39 were given what's known as a Hall Pass by the Speaker. They are from districts that Senator McCain carried in last year's Presidential election, and so they are concerned about their re-election. And this has become such a partisan effort that they were given a pass to insure that a vote for health reform wouldn't be taken against them next year. But it still was a very slim margin. But we believe -- everybody in Washington says well 20 years from now, nobody's going to remember who voted against it.

One Republican who represents an African-American district in New Orleans voted for it. So it's definitely become a

partisan issue.

Now, right now in the Senate, we know it's in the House Bill because the House passed it. In the Senate, the two bills are being merged, and the merged bill is being evaluated by the Congressional Budget Office to determine a cost estimate. Everything in this bill, in this effort, is driven by what it costs. President Obama said it must be deficit-neutral, meaning it can't add to the deficit. So everything has to be paid for either by increases in revenue or by cuts. And most of the cuts have come from provider payments.

And he's also said in his speech to Congress that the bill should cost no more than \$900 billion over 10 years. So we have to come up with \$900 billion over 10 years.

So a couple of things we know that differences between the House and Senate approach to paying for this.

With respect to revenue, the House Bill imposes a surtax. It's called the Millionaire's Surtax on individuals with annual incomes of \$500,000 or more or families, couples with annual incomes of a million dollars or more.

Now, 97.3% of individuals in this country would be exempt from this surtax. So it's not going to affect the overwhelming majority of people. However, most people don't think that the ultimate bill that President Obama signs will contain this

surtax because everyone in the Senate hates it, including a lot of Democrats. They have no appetite for passing this surtax.

The Senate's approach is very different. It imposes a 40% excise tax on what are known as Cadillac plans. And Cadillac plans provide very rich benefits. The surtax, a lot of people in unions, state workers, have these types of plans. So the unions aren't thrilled with them.

The standard for the surtax, it would be 40% on a plan -- an individual plan that's \$8,000 or family coverage if it's \$21,000. So it's unclear what will happen. That will probably be an issue that is debated on on the Senate floor and it ultimately might be changed.

So most of what I'm going to talk about today, because we know it's in the bill is called the House Bill, called the Affordable Healthcare for America Act 2009, it basically sets up what's known as a universal mandate, which is called shared responsibility. And that's intended to cover as many people as possible.

The House Bill adds about -- covers an additional 36 million people. It does so by providing significant federal subsidies to people of low incomes. It also expands Medicaid eligibility, which I'll talk about in a second. And it sets up a national insurance market exchange, which is really like a

marketplace where private plans and a public option in the House Bill run by the government and nonprofit co-ops will all operate, will have to meet certain standards to participate in this exchange, and people will buy the insurance in the exchange.

Initially uninsured people will purchase insurance through federal subsidies. Ultimately small employers will be able to use it. And then larger employers will be able to purchase insurance through the exchange.

With respect to what's important to people with disabilities and health reform, first and foremost is insurance market reform. All of what I'm going to talk about with respect to insurance market reforms are in the House Bill and almost all of them, I'm confident, will be in the Senate Bill.

First and foremost, pre-existing condition exclusions will be outlawed, will be absolutely prohibited.

[Applause.]

Yeah, that was very, very significant.

Secondly, discrimination based on health status will be prohibited.

[Applause.]

Thirdly, and this is really important for people with disabilities, there will be annual and lifetime caps on policies

will be prohibited. Many people don't realize that many insurance policies have an annual cap of -- only covers \$50,000 or a lifetime cap of a million dollars. And if you have a significant disability where you need a lot of medical coverage, you know you could be out of luck after 15 years.

So annual and lifetime caps are prohibited.

And, lastly, the law requires what's known as guaranteed issue, where they can't rescind your policy from year-to-year.

So these are obviously very significant. We call it a sea change. And insurance market reform for people with disabilities.

Now, the other important thing, I told you we're going to have a national insurance market exchange. That has to meet certain standards.

One of the other things I should mention, it's not in the slides, but Steve talked about medical bankruptcies. There will be an out-of-pocket cost initially in each of the bills. I think the House Bill is \$5,000 for an individual and \$10,000 for a family, which may sound like a lot, but a lot of people have medical bankruptcies of 50 to \$100,000. So there will be an out-of-pocket limit to prevent medical bankruptcies.

In terms of the exchange, the standards are very important. And one of the most important things for the disability

community is the essential benefits package. We worked very hard on this to make sure that the benefits package meets the needs of people with disabilities.

So on the House Bill, it covers traditional things like inpatient, outpatient services, x-rays, labs, prescription drugs, pediatric care, including vision and dental services for children up to age 21, I believe, mental health and substance abuse services in compliance with the Mental Health Parity Act, which passed last year and I know many of you in the room probably worked very hard on, and it also includes rehabilitation and habilitation services. Habilitation services are very important for people with intellectual disabilities to allow -- as well as physical disabilities -- to allow people to maintain and retain function.

In addition, one of the most controversial things that we got include -- that is absolutely essential -- is durable medical equipment, like wheelchairs. How anybody thought we could have a health reform bill without coverage of wheelchairs was beyond me, but it was an effort, because of the perceived increased cost.

So the Bill, the House Bill, specifically includes durable medical equipment, prosthetics and orthotics and related supplies. So that is really important. So that means that all

plans in the national exchange will have to include all of those benefits.

The plans will be able to offer different levels of coverage, and the levels of coverage will differ depending upon their cost sharing. But they will have to have the same benefits.

The other thing that the House Bill does that is really significant and quite historic is in the area of health disparities. You probably know that there's a lot of research done in the area of looking at racial and ethnic minorities and the disparities and the access in quality of care they receive, the differences in the access to quality and care they receive as compared to the general population.

Well, no one has really looked at people with disabilities in a comprehensive way. We have anecdotal information, but we've never looked at people with disabilities with respect to health disparities in terms of access and quality of care they receive.

So the House Bill includes disability as a health disparity for the first time ever. So that research will be done on access and quality of the healthcare they receive, and that research will enable us to lay a foundation for the types of improvements in the future and access and quality of health care

for people with disabilities. So that's really what's significant.

And, thirdly, the bill does something that I'm sure all of you can relate to, it requires the U.S. Access Board to, which is a federal entity, to develop standards for what an accessible diagnostic or other type of medical equipment would look like. So what is an accessible examining table? What is an accessible x-ray machine? Specifically in terms of inches and height and all that. What is an accessible mammography machine? All of those types of equipment, medical equipment and diagnostic equipment will have to be accessible when they're newly purchased under strict compliance with these guidelines that are going to be developed. That's sort of like an ADA-related issue, as you can see.

So that is in terms of the big picture from the disability community's perspective, there are very exciting Medicaid provisions. In addition to the federal subsidies I've talked about to get people covered, there's a significant expansion to Medicaid eligibility, up to 150% of the federal poverty line in the House Bill. And that covers about -- income of \$33,000 a year for a family of four. Right now a lot of states, SSI covers 74,000 for -- 74% of poverty.

So 150% of federal poverty is really a significant

expansion. And the most significant thing about this is it comes with -- most of this will be the expansion will be paid for by the Federal Government initially for the first few years, with 100% Federal match and then it goes down to 91%. So the governors will not be bearing the brunt of this expansion.

Secondly, and this is very important for increasing the quality of care for people with disabilities in Medicaid, it requires that the Medicaid reimbursement rate for primary care providers, specifically physicians, be increased from the Medicaid rate, which is very low, to the Medicare rate, which is higher. So that will make it -- and that comes with significant federal funding, as well. It's similar to the eligibility funding, about 100% for the first few years and then the Federal match of that, 91% federal dollars. So that is really critical, because all of you know, for anyone on Medicaid, it's very difficult to find a physician because the reimbursement rates under Medicaid are so low.

And, thirdly, the House Bill prohibits beneficiaries for being charged for purposes -- remember, I said one of the purposes of this bill is to focus on wellness rather than sickness? Well, this is one of the ways we focused on prevention. And the types of prevention that are going to be covered will be determined by an advisory taskforce that exists

as part of the Department of Health and Human Services under the Public Health Services Act.

And, lastly, under Medicaid, and this is very important for all states, and I know here in Indiana, because like other states, you have a significant budget deficit due to the economic recession. There's a six-month extension in the increase in the Medicaid matching rate that was enacted in the Stimulus Bill that President Obama signed into law in February. It's called the American Recovery and Reinvestment Act. That stimulus -- initially it provided \$87 billion, the increase in Federal match for two years. So this expands that at the same rate for an additional six months through the first part of 2011.

Okay. Now we're going to shift and talk about long-term services and support. And these are very important to people with disabilities, obviously. It's not exactly my area of expertise. It's my colleague, Marty Ford, who was a couple of years ago, she's been working very hard with other disability groups and the Asian community in a very effective collaboration to try to get long-term services initiatives integrated in the health reform bills in the House and the Senate.

They initially sent a letter to President Obama about the importance of this. It was signed by 95 national organizations

that worked very collaboratively on the Hill. And their goal has been two-pronged: One, to enact a new insurance program to cover long-term services and supports and, two, to eliminate the Medicaid's institutional bias, which we all know has been long-standing.

So the first, with respect to the new long-term services and supports insurance program, it's called the Class Act, the Community Living Assistance Services and Supports Act. It was initially introduced by Senator Kennedy. And it's really become part of his legacy. And those who are working on it really see its enactment. Many of his staffers are still working on the Hill and working very hard to see that become part of healthcare reform.

What it does is it sets up a new voluntary insurance program that's self-financing, which means individual employees would pay for it through a payroll deduction, sort of like a 401(K) deduction. You have the opportunity to opt out of paying for it. Like you have the opportunity for 401(K) retirement account. Would cost about \$120. It's unclear what the premium would be.

So you pay a monthly premium for five years. After five years, you'd be vested. And based on your functional need after five years, you'd have to have a functional need in two or three

activities of daily living, you'd get a cash benefit and you can use it for anything you need, whether it's paying a home health assistant, a personal care attendant, doing modifications on your home, to making them accessible, someone to help you clean, whatever you need to enable you to be independent and remain in the community. And the benefit you get is unclear. It's probably between 50 to \$100. And this is going to be worked at in regulation.

But the brilliance of this is that it's self-financing. And there's solvency positions. So it has to be solvent for 75 years. It rolls over 75 years. This one, the Health Education Pension Committee, which Senator Kennedy had chaired and incorporated into his bill and we're working on getting it in the merged bill, I have to unfortunately be the bearer of bad news. Your Senator, Senator Baye, has raised concerns about this about the solvency about this, the viability of this, which is unfortunate.

So we hope in your advocacy, you'll tell him how important it is to keep people in the community and allow them to be financially viable and to provide their own services and supports, because many people in the long term can't get long term care insurance.

I , because of underwriting practices by long term care

insurance companies, can't -- even if I spent \$10,000, \$20,000 in premiums -- couldn't purchase the coverage because they write people with disabilities off. They don't want to cover us.

So we have to figure out a way to do it for ourselves, and the CLASS Act is the way to do it.

And the long term care insurance industry has really brought out all their guns in posing this. And they're spending about \$5 million in ads, and they've got all kinds of people on the Hill making phone calls. And they're taking this quite seriously.

So we're hoping that it will get in a merged Senate Bill. It is in the House Bill. And it would really be transforming for long-term services and supports. And most of all, over time, it will save dollars in Medicaid. It relieves the pressure on Medicaid.

Because most people don't realize that currently Medicaid is the only law that provides long term services and supports. And Medicare doesn't. A lot of seniors think that Medicare provides long term care, and it doesn't. And the only way, as you know, that you can get long term services and supports under Medicaid is to spend down, to impoverish yourself.

The CLASS Act doesn't require you to impoverish yourself. You can keep working. You still get to keep your assets. So

this is really a transformative way of looking at remaining independent and staying in the community and we think makes excesssably brilliant public policy.

The second effort with removing the institutional bias in Medicaid, many of you are familiar with the Community Choice Act? ADAPT and the Arc and ECP and NICL and many people in the disability community have been working on this for a long time.

Unfortunately -- and they have been very effective advocates -- unfortunately, the way Medicare law works, nursing home services are mandatory under the law. Community-based services are optional. And that's just the way the law was set up in 1965. And there have been changes along the way with respect to Medicaid waivers, but it's been very difficult to turn the whole system around so that the community would be mandatory and institutional would be optional.

So because of that bias, people with disabilities and their families really don't have a choice. So the Community Choice Act really intends to eliminate that bias by making community services mandatory rather than optional. And it provides a very comprehensive benefit from personal care attendants to any assistance in the activities of daily life, any type of personal assistance. Regardless of what your disability is, the type of assistance you need, the Community Choice Act will provide it.

That's the good news.

The bad news is it's very costly. And when the Congressional Budget Office did its estimate, I think the estimate was about -- it was very costly -- it was several billion dollars and \$20 billion or perhaps more over 10 years. And so it was too much for Congress to conquer in this health reform effort.

So since we couldn't do the Community Choice effort this time, the decision was made to take a first step and to do what's called the Community First Choice option. So rather than a mandate, this is an option which states will be allowed to take up. It provides the same benefits regardless of what you need. And there's a sweetener in it: It gives an increase of a 6% in Federal match to the states who take up this option, as an incentive to get them to take it up.

There are a couple of issues that are being worked out. It sunsets after five years. And we're working very vigorously to try to get rid of those sunsets because that will be a disincentive to the states. And it doesn't start until 2014. And both of those issues were put in as a way to decrease the cost. So the disability community is working very hard to make it -- eliminate the sunsets and make it start earlier.

It's in the Senate Finance Committee bill. We're working

hard to make sure it's in the merged Senate Bill. And the Senate Finance Committee put this provision in after the House had done all its cost estimates, so there's a sense of the Congress in the House Bill that this should be approved. And there's a lot of support for this in the House. So we'll work hard, but we anticipate that the House would accept this provision.

So what are the overall challenges with getting health reform? Not just the disability provisions, but the overall bill enacted.

First, as I mentioned earlier, is paying for it. President Obama said it can cost no more than \$900 billion over 10 years. So we have to come up with an agreement on revenues and provider cuts. Everything has to be offset. And as you can imagine, that's an incredible cat and dog fight. But we try not to get into, except to make sure that beneficiaries' benefits aren't cut for people with disabilities, and so far we've been very successful in working with the AARP and they've endorsed that. So we've been successful on that front.

There's been a lot of controversy, as you probably read in the paper, about whether to include a public option, and what type of public option should be included. Should it be a public option that Medicare -- is like Medicare? Or it should be a

public option that's just like the private plans in the exchange but the Federal Government initially pays the startup costs? So that's been a big bone of contention.

And the argument for a public option is that it will increase competition with the public -- with the private plans and therefore decrease cost.

Well, the private health insurance industry, because of that reason, doesn't want increased competition because they think they'll lose money. So that's been a big bone of contention.

Also, it's been rather tricky, as you can imagine, to juggle all of the Congressional committees around. And they've all had different provisions. And there are a lot of egos. And it's been a real challenge not only for the Members themselves and their staff, but for the disability community to make sure that our issues were covered in all committees.

So in terms of where we are, the House passed it. We're waiting for the Senate merger. And the Senate is a much more deliberative body. There's been efforts all along to try to make this a bipartisan effort. But from the getgo, unfortunately, the Republicans in both the House and the Senate have opposed this effort. The Republicans in the House put forth a bill that only covered 3 million people. And the press

didn't even take it seriously. There was a vote on it. It was defeated overwhelmingly. So unfortunately there's been no bipartisan cooperation.

In the Senate, in order to move a bill and avoid a filibuster, meaning ongoing debate that's like being stuck in quicksand, you need 60 votes. And there are a lot of conservatives and moderates in the Senate Democratic caucus as there are in the House. In the House, they call them blue dogs.

So in both the House and the Senate, there's been a real challenge for the leadership of both bodies to get -- achieve consensus between the progressives and their caucus and the moderates and the conservatives. And right now the Senate Majority Reid has a significant challenge to try to get enough votes on specific issues to get the bill passed and get 60 votes. So he's asked the Congressional Budget Office to not only do an estimate on the entire merged bill but on different options for different provisions. So different provisions that are not acceptable to the moderates or the conservatives, he can just offer alternatives.

So we anticipate that the bill, the merged bill, will be introduced probably right after Thanksgiving. It will be on the Internet along with the Congressional Budget's estimate for three days before the first vote on a motion to proceed is

taken. And then there will be Senate debate. And Majority Leader Reid has said there will be time for lots of amendments, whether they be offered by Republicans or Democrats. So there will be at least two weeks of debate, if not three.

Their goal is to try to have the Senate vote on this, a final bill, before Christmas. And then after that, in January, they'll either have to do a conference to resolve, between the House and the Senate, to resolve the differences between the bills, which I'm sure will be many, or will do what is called ping pong.

If they decide not to do a conference, they'll -- the Senate Bill will go back to the House for a vote. If it's changed, then the House Bill will go back to the Senate and they'll go back and forth until they come up with one bill that's identical from both Houses that President Obama can sign.

And as President Clinton told the Senate Democratic caucus last week, the economy really demands that health reform should be passed. He encouraged them to not let the perfect be the enemy of the good. And a bill that's imperfect is better than a bill -- no bill at all, because an imperfect bill can always be improved.

So we are fairly confident, although we're going to need your help at the grassroots level, to ensure that the best bill

for people with disabilities is passed.

So thank you very much for your attention. And I look forward to the discussion.

[Applause.]

>> Steve: Thank you, Liz. That gives us a lot to think about, doesn't it?

And now I'd like to introduce to you a panel of Indiana experts in healthcare and policy who are here to help continue this conversation with Liz and help translate that information for you and me here in Indiana.

So let me introduce to you in the random surprise order our speakers. First, a change on the agenda. We have John Dickerson listed, who was not able to be here today. So in his place is Kim Dodson. And Kim, as you may remember from yesterday, is the Associate Executive Director for the Arc of Indiana, which is a statewide membership organization of advocates on issues important to people with developmental disabilities and their families. And her job is to focus on public policy at the state and national level.

And second we have Nancy Jewell. Do it wildly. Kim Dodson, wildly. Nancy Jewell, wildly, is the President and CEO of the Indiana Minority Health Coalition, a statewide, nonprofit organization that she helped organize that exists to

eliminate health disparities through advocacy, education and awareness, research and training. She's also an active member of the American Public Health Association and serves on the National Association of State Offices of Minority Health.

Next is Julia Vaughn, who has been an advocate working in the public interest for more than 20 years. Currently she serves as a Policy Director for Common Cause Indiana where she lobbies the General Assembly and leads grassroots lobbying efforts on campaign finance reform, lobbying and legislative ethics reform, public records and open government and election reform. She currently serves as a health policy consultant for the Citizens Action Coalition Education Fund, the research and education arm of CAC. She serves on the steering committee of Hoosiers for a Common Sense Health Plan and is recognized as one of Indiana's leading advocates for healthcare.

Next is Donna Gore Olson representing Family Voices of Indiana, which provides support for families with special healthcare information by sharing information related to families for input into policy, procedures and partner decisions that affect families with children who have disabilities, developmental delays or significant medical needs. Donna, as the parent of an adult with a chronic medical condition, has been active as an advocate for over 20 years, especially with

regard to children with special healthcare needs. In 1987, you may know Donna helped found the Indiana Parent Information Network, now known as the About Special Kids. And she's also currently working on a project to help protect a project helping families with infants born with disabilities.

Also Dr. Sarah Steizner is a Doctor of Vanderbilt University of Medicine. Following her residency, she was chosen to be Chief Resident at the University of California in San Francisco. In 1998, she joined the faculty of the Department of Pediatrics at the IU School of Medicine. She's currently a Co-Principal Investigator on the Partnerships for Change, which is a Dyson Initiative, the Training Initiative at Indiana University, and serves as a Co-President and Legislative Liaison for the American Academy of Pediatrics. She's a primary care provider for a large Latino community at Wisher Hospital.

So you can see we have quite an esteemed body up here that has information and knowledge around healthcare, and so we're going to ask these folks to comment on what they heard from Liz Savage and get some conversation with her and we'll listen in on the conversation.

So let's start with Julia.

>> JULIA VAUGHN: Okay. Very good. Well thank you all. It's a pleasure to be here. I don't know how many years I've

been doing the Governor's Planning Council Conference, but it's been a long time. So it's always my pleasure.

I am Julia Vaughn. I am a healthcare consultant. I work for the largest consumer group in the state, Citizens Action Coalition. We're probably best known for our work on utility issues, but we work on others, including universal healthcare. Is that better? Poor Nancy will be deaf after this. I should have told the person sitting next to me needs to bring ear plugs. So we take things from a consumer perspective.

Steve also mentioned the coalition that we belong to that I serve on the Steering Committee, and that's Hoosiers for a Common Sense Health Plan. We are a coalition of organizations and individuals. We have about 70 organizations that participate. And it's a really diverse group. We have healthcare providers, consumers, the labor community, the disability community, some community groups. So it's a very broad perspective. But what we advocate for is a single payer healthcare system, a system like Medicare, an improved and expanded Medicare program, that all Americans would be eligible for.

Steve -- I really appreciated Steve Tilden's remarks from T.R. Reid's book because I think it's really important that we look to other countries for guidance here. My big concern about

what's going on in Washington, D.C. right now is they are reinventing the wheel. They are coming up with this Rube Goldberg type system that is really going to be complicated. And it just doesn't have to be that complicated.

We need a system that everybody belongs to: Rich, poor, people with disabilities, people without disabilities, people in California, people in Washington, D.C., North Carolina. We believe the ultimate insurance pool is everybody in the United States. Everybody paying into the same system.

I really get concerned when people talk about free healthcare, because there isn't any free system out there. But we believe that access to healthcare is a basic public good. That, like Steve made the comparison, it is very similar to public education. That it's the same thing as having safe roads and bridges that we can travel on. That it's very similar to -- you don't buy private health insurance or private fire insurance. We did that in the early days of this country and it didn't work out very well.

It used to be that there weren't public fire departments that you could call when your house caught on fire. You had to have private fire insurance. And you can understand how that wouldn't work, right? Especially in crowded urban areas, one person's house caught on fire and they didn't have private fire

insurance and so the entire block burned down. That's basically what's happening with our healthcare system. Those who don't have insurance still get care, but they get care in the most inefficient and expensive way that there is, and the rest of us with coverage pay for it. We have the most expensive and the most inefficient system, and we really shouldn't call it a system because it isn't a system. It is a mishmash of different programs that were passed at different times to serve different constituencies. And it's like a house of blocks that has been stacked up and it is getting ready to topple over.

So we really think that the Congress is overcomplicating something and that we should follow the lead of every other industrialized nation that has said yes, access to healthcare is a basic public right. It is a basic public good. And we are going to make everybody eligible. And we are going to fund it in the most broad way that we fund basic public goods, and that is through the tax base.

Now, sadly, that is absolutely not the direction that the United States Congress is taking it.

[Applause.]

What the United States Congress is prepared to do, at least in the House Bill, in the Senate, if anything, the Senate Bill will be poorer, from our perspective, from a consumer

perspective. They are going to make it a law that you have to have private health insurance. This is called an individual mandate. So it will be the law that you have to go out and purchase private health insurance. We think that builds on the worst part of our system.

You know, one of the reasons why we're spending 16% of GDP on healthcare and the rest of the industrialized world is below 10%, yet managing to cover all of their citizens is because we have this wasteful private health insurance industry.

You know, as Americans, we have been trained from birth to believe that private is always better than public; right? Private's always more efficient than public. That has been drilled into our brain from infancy. And that may be true in some areas, but it is absolutely not true when it comes to healthcare. Private health insurance is much less efficient than the Medicare program.

Let's look at overhead. Medicare spends about 3 cents of every dollar on administration. You compare that to the most efficient private health insurer, a large group plan, they're not doing to spend less than 15 cents out of every dollar on administration. And when you understand how they do business, it's easy to understand why they are so inefficient. They've got to do all this underwriting, risk adjustment. They want to

make sure no sick people get into the plan; and then if somebody sneaks in, they've got to figure out how to kick them out or deny their claims. So it is an expensive, expensive business.

Let's also not forget that they're in it for profits. The health insurance industry, private health insurance industry in this country has evolved tremendously over the past 20 to 30 years. When private health insurance first started back in World War II, and it was an accident, sort of an accidental thing that we even have this beast of an industry is because of wage freezes that were put in effect during World War II. But in that time, most of these insurers were not-for-profit. And so they didn't have to -- in addition to all of the underwriting and risk adjustment and making sure that they don't have to pay out any claims, they didn't have to worry about turning a profit and paying that out to shareholders.

But that has changed over the years, and now the vast majority of private health insurance companies are for profit. So they're in it for the money. And that becomes the paramount priority. It's not paying claims; it's making sure that your shareholders are going to have a profit at the end of the day.

In the United States, we spend 31% of our total healthcare spending. Over a couple, \$2 trillion this year, nearly a third of that, though, does not pay for any healthcare service; it's

eaten up through administrative costs.

And so we believe that the current plans that are being talked about in Washington, D.C. are going to strengthen the worst part of our system, that's private health insurance. What industry wouldn't want a federal mandate that you have to buy their policy?

Now, I will agree with you that outlawing pre-existing conditions, saying they can't rescind policies, all of the insurance market reforms that Liz talked about, those would all be very positive things, but only if they come with one other new law, and that would be a limit on what they can charge you in premiums. Because make no mistake about it, they're still going to have to make money. Their business model isn't going to change. They are still going to be for profit.

Now, there is some talk about having language in legislation that would say they can't spend any more than 15 cents out of their premium dollar on administrative costs. I've seen that language here in Indiana, and the industry will fight it. And I'm ready to bet that it won't end up in the final bill.

So an individual mandate that forces consumers to buy a private health insurance plan -- now there will be subsidies available for people who can't afford it, but that's going to be

the \$100 million question: At what level is health insurance unaffordable and you're eligible for a federal subsidy? At what income level are you not eligible for the federal subsidy to help you pay a price of that overpriced health insurance premium?

You know, it's been interesting to me that much of the debate, particularly in the Senate, has been what kind of health reform can we afford as a country? And that is absolutely an important question. But the answer to that question is not a system that is based on wasteful, profit-driven, private insurance; it is a system that spends its money delivering healthcare services to people, not generating profits to stockholders, and certainly not spending or wasting nearly a third of your total healthcare dollars on red tape, on paperwork.

We can't afford to do it in the way that Congress is talking about it, and we're very disappointed that the debate really hasn't included a Medicare-for-all or a single-payer approach.

I do want to let you know that there is legislation, H.R. 676, the lead sponsor is John Conyers, a Democrat from Michigan. And there are 90 other cosponsors on this bill. So there is significant support, certainly within the progressive caucus,

for this approach. But as you know, even a public option, which is really Medicare done light, light, light, has been hugely controversial.

I do want to mention before I stop, and I want to give the other panelists a go at this, but as was mentioned in my introduction, I wear a couple of hats. The other hat, besides my healthcare hat, is a good government hat.

And I would just caution that we've got to be very wary of health reform when we know that the healthcare special interests -- and that's basically pharmaceutical companies, your medical equipment manufacturers and your drug companies -- are spending \$1.4 million a day -- a day -- to influence this debate. Max Baucus, who is the Chair of the Senate Finance Committee, his top aid, the woman who really wrote the draft of Baucus' bill, does anybody want to guess where she worked before she went to work for Max Baucus? Good guess. But the insurance industry. And in fact, she worked for Wellpoint, the largest health insurance company in the world, that happens to be headquartered right here in Indianapolis, Indiana. I am very wary of any legislation that comes from the desk of somebody whose orientation is from the private health insurance industry.

I also want to mention that Senator Evan Baye, he's mentioned up here on the table. He's going to be a major figure

in the debate.

>> His wife.

>> JULIA VAUGHN: Exactly. You already know it. He has a tremendous conflict of interest on this issue. His wife Susan Baye has been on the Board of Directors of Wellpoint.

>> We can hope she won't be a problem in that area.

>> JULIA VAUGHN: Make your own conclusions. What you need to understand is that in her 10 years on that Board, the Baye family has pocketed about \$2 million. She gets paid to be a Board Member and she has access to a tremendous amount of stock. And that's really where the bulk of that 2 million came from, her ability to sell the stock. I would suggest to you that somebody who has millions of dollars of their company's profits on the line probably isn't unbiased in this debate. The Senator has told us "oh this really doesn't have any impact on my thinking". How would you react if you had \$2 million on the line?

So as constituents, I think that we have to be very vocal. Again, we are very wary of this bill. As Liz said, I think we always have to remember we can't let the perfect be the enemy of the good, but from our perspective this legislation just isn't that good. It takes us in the wrong direction. It takes us away from the concept of healthcare being a basic public good

and a basic public right. It treats it like a commodity. And we had enough of that. Thank you.

[Applause.]

>> Steve: Thank you, Julia for your passionate response.

Liz, do you want to say something in response?

>> LIZ SAVAGE: Can you hear me? I think all the consumer community basically agrees with you with respect to single payer would be better. However, as you intimated, there's no political will to do this. Even though there's 100 or so cosponsors on a House Bill, there was a Senate Bill introduced for single-payer by Senator Bernie Sanders of Vermont, and it has no cosponsors. Senator Kennedy a few years ago introduced a Medicare-for-all bill. You know that Senator Kennedy was one of the most liberal members of the Senate but was also one of the most highly regarded for his expertise. But he got absolutely no, zero, cosponsors on that bill. So, unfortunately, at this point in time, there's no political will to do single payer.

And I just wanted to say one thing about the individual mandate. People will have to have insurance. But if you have Medicaid or if you're a Medicare beneficiary, you're allowed to keep your Medicaid or Medicare; you're not required to buy private coverage.

>> Steve: So there's lots of information to figure out,

isn't there? This is really quite complicated. And I'm guessing there's a room full of 100 different individual questions about how to sort it out. And the fact is we don't have a bill that's passed yet, so it's important to keep listening what the information is. So when you talk to your Representatives, you have a lot of good questions to ask.

So let's listen to some other panel members who could help us think about different perspectives.

>> SARAH STEIZNER: I'm hearing a significant amount, but I don't consider myself an expert. Is this on? Here we go.

I want to preface my comments by saying I am not an expert and I'm learning a tremendous amount by sitting here and listening to the people. It's an amazing experience to see your response and what impassions you all, too. So that's very helpful.

I guess what I can add is the provider perspective. I also want to say that I am a salaried physician. And so that's a beautiful thing because I don't have to fight with insurance companies.

But from the pediatrician's perspective, it's really funny to hear how they feel about this whole debate. In some ways you would think that they would really embrace a single payer because the hassles of dealing with insurance companies, as you

all know, are tremendous. You all have to deal with your insurance company, and that's a tremendous energy and time drain. But pediatricians deal with multiple groups, and each has a separate set of forms, formularies, procedures. And so you can imagine how much of their day and their -- how much overhead they spend on dealing with just getting paid for the work that they do.

The other thing is that they're paid in very arbitrary ways. So that oftentimes we are much better reimbursed for little procedures and things that are very easy to sort of document rather than communicating with subspecialists, care management of patients with complex conditions, and those sort of things. And so it's quite frustrating to not be able to spend money on time that people would like to.

The other thing you would think is -- and I agree with the comments our speakers have said, that you would think that pediatricians would want to have a system like Medicare or Medicaid, but they fear that in some ways because while private insurance companies are there and a huge burden to deal with, they at least pay at a reasonable rate. And the issue with pediatricians especially and Medicaid is that Medicaid reimburses on average about 60% of Medicare and even less probably than private insurance companies. And so many

pediatricians, especially rural areas, and you all may have dealt with this, can't -- they can't even meet their overhead much less pay their own salaries if they were to accept over a certain percent of Medicaid patients.

And so it's really an access issue. It creates a huge burden on communities when children and individuals with Medicaid can't access the care that they need, and that's primary care.

It was interesting. I'm a primary care provider, and so I didn't really know what it was like for subspecialists. I don't think anybody here feels sorry for pediatric orthopedic doctors; they are all doing fairly well. But they would like to be able to see everybody. But pediatric orthopedic doctors -- I wrote this down because I was so shocked -- Medicaid pays them 23% of what Medicare pays for the care that they give Medicaid recipients. And so you can imagine how difficult it is for them to open their doors and provide access.

And so these are sort of the difficulties that providers face. I'll put in one more -- my other hat is the President of the American Academy of Pediatrics. And our national organization is really doing what I consider a fabulous job keeping us informed about the ongoing, constantly changing, complicated nature of this healthcare reform debate. And we

very much appreciate it. And their effort really is to provide the best coverage for children, the best universal coverage that mandates age-appropriate care within a medical home. And so I'm very proud of our organization and would be willing to answer any questions where that comes into play.

>> Steve: So it sounds like there's a variety of perspectives. We all come to this with important questions about whether you're a consumer or provider or an advocate, et cetera. So this is good. Good information. Good discussion. Did you have any responses to that, Liz? How about Nancy Jewell from the Indiana Minority Health Coalition, what is your perspective and take?

>> NANCY JEWELL: There is a lot of information on healthcare reform. I didn't realize all of the debates going on out there. I'm a consumer advocate. Our whole initiative is to eliminate health disparities in racial and ethnic minority populations in Indiana. We have 47 sister organizations in other states. Here in Indiana, we are in 29 counties and we directly fund 23 local affiliates to provide services in those counties.

And our whole mission is to eliminate health disparities by making sure that people have access to quality, culturally competent and affordable health services. So however we make

that happen, we'll be happy. We're not in the middle of that debate.

But I have a couple of questions. You mentioned it briefly, Liz. Even if people have access or have health insurance, do we have the capacity in our healthcare delivery system to provide services?

And I know when here in Indiana you have over 40 counties that have health care professional shortage areas. You have more than that that are medically underserved areas, which means you don't even have a medical facility there. And then we look at mental health, you probably are talking about 50 plus counties.

So it becomes a concern because when people believe -- it's not just an insurance issue; it's a capacity issue, as well. And when people don't have access to health services and you don't have the capacity there, then that's very disappointing.

So I would like for you, as far as the legislation, what is looking at -- outside of just trying to get more primary care docs out there, you don't have nurses and other folks that you need to deliver care.

And then the second question you mentioned, and I can't remember which part it was, but that provider reimbursement is going to be possibly looked at as possibly being cut. And I

know that even with Medicaid and Medicare patients, providers have opted not to accept them because of the reimbursement issue. So how do you deal with that if you're trying to increase delivery?

[Applause.]

>> LIZ SAVAGE: Those are terrific questions. There will be some -- with respect to physicians -- some loan forgiveness programs for med school. Because as you know, people incur incredible debt in paying for their med school tuition with incentives to go to rural areas.

There will also be new categories of coverage for like physicians' assistants to enable -- to lessen the pressure on physicians in terms of their patient load, to enable nurses and other assistants to take on some of those tasks. And that will be reimbursable through Medicare.

And provider -- Medicaid, the doctor noted, the Medicare provider physician reimbursement rate is incredibly low. Indiana is probably different from every state. There are like 50 Medicaid programs in this country, since it's financed jointly by the Federal Government and the state. So every state Medicaid program is different. But in the House Bill there's a provision to raise the Medicaid reimbursement rate for physicians to Medicare rates, which should increase the -- allow

people to access physicians more easily.

With respect to provider cuts, since there's going to be an individual mandate where everyone -- almost everyone will be covered, there are going to be cuts, over time, not immediately, to what are known as disproportionate share hospitals, or "Dish" hospitals, who treat many of the uninsured in this country right now in their emergency rooms and elsewhere in their hospitals. And that's in recognition of the fact that many of the people they treat will either be covered through Federal subsidies in the exchange or through the expansion through Medicaid. But that's not going to happen immediately overall.

And the other provider cuts are going to be small with respect to Medicare over the next 10 years. And hospitals and the rehab -- the durable medical equipment industry have agreed to those cuts because they are small.

Did I answer the question?

>> NANCY JEWELL: I guess the one part that isn't answered, if you don't have medical facilities to go to, how is that dealt with in the Bill?

>> LIZ SAVAGE: There's a big expansion for community health centers in the Bill.

>> AUDIENCE: Can't hear.

>> LIZ SAVAGE: There's a big expansion of community health

centers.

>> The question wasn't heard.

>> LIZ SAVAGE: The question is if you don't have hospitals, if you don't have medical facilities, how does that help?

>> Steve: And is that covered in the Bill was the question.

>> LIZ SAVAGE: And my answer is there's a big expansion of community health centers in the Bill. And there is recognition of the need to expand hospitals in rural communities. Many of the big players, Max Baucus was mentioned, well, he comes from Montana. It is a very rural state. So rural health providers, their concerns have been addressed in this Bill.

>> NANCY JEWELL: Capacity is always an issue with me. I had another thing, if you have facilities where you don't have ramps, you don't have signage, you have staff that's not trained to deal with a person with disabilities, all those are capacity issues. And so my whole question is: Are all of those things being addressed in the legislation? Because I think that it's important to make sure you have capacity before you lead people to believe they have access.

>> LIZ SAVAGE: I'm glad you asked that question. Did everybody hear that? About access? Not only with respect to physical disabilities, but sensory, et cetera?

Whenever you're building something or funding something, a current facility, you're building a new facility with Federal dollars, it's covered by Section 504 of the Rehabilitation Act and has to be built in compliance with specific technical standards, not only with respect to physical access but with sensory access. And 504 requires interpreters, et cetera.

If it's built totally with state dollars or private dollars, it has to be built in accordance with the strict requirements of the Americans with Disabilities Act.

And the Justice Department and HHS, the Office of Civil Rights, HHS, would really welcome complaints of either existing or new facilities that you know of that don't comply or are not accessible to people with disabilities regardless of what their disabilities are.

The Disability Rights Section of the Justice Department is really open for business again, and they are looking at a lot of hospitals around the country, current existing hospitals, with respect to access, not only physical access but communications access. So to the extent you know of any that are not accessible, you should -- they would welcome receiving complaints about that.

>> Steve: I'm struck by the complexity of this issue, that there's so many different perspectives and so many questions

about how do we make sure that we have the right bill? And what I'm aware of is that the current Bill that's been passed by the House is how many thousand pages?

>> LIZ SAVAGE: 2,000.

>> Steve: 2,000 pages.

>> LIZ SAVAGE: But for all of you that use computers, there's an edit function. Under "edit," it says "find." You put in a word, key word. You can find a word.

>> Steve: So you have access to the Bill online. But what I'm struck by is because it is so complex, and it apparently is taking a lot of words to try to sort out what it is, which is one of the dangers, as Julia was talking about, is that maybe we're making it more complex than it needs to be. But we got to ask the questions.

So let's hear from Donna Gore Olson continuing from the access question and from about a kids perspective from Family Voices.

>> DONNA GORE-OLSEN: Can you hear me?

>> Steve: You have to talk.

>> DONNA GORE-OLSEN: Can you hear me? I think there's a couple of things that I think is absolutely critical in whatever -- what Liz commented about earlier in terms of appeals or filing complaints. It goes back to that old issue of

providing information, whether it's to consumers, to families or to our physicians, in terms of training everybody to understand what these rules are all about and what you can do individually or as a group to make a difference.

I think that from my perspective, as I worked not only coming from the family perspective with my own children, working with other families, but in the last five years working at the medical center where we're trying to train physicians to understand what many of us already know. But without working together, particularly around health care reform, but what is acceptable and not acceptable?

I appreciate Liz's comments about making sure that we reach out to the rural communities; but quite frankly, the little babies I'm working with in the newborn intensive care unit can't go home to a physician assistant, they've got -- they're too complex, they're too fragile. So how are we going to make sure that this system works?

I'd also like to comment that it has always been my interest in looking at reimbursement rates. I've heard for rates for how physicians and hospitals have said there's a huge difference between Medicaid reimbursement and commercial insurance reimbursement. I'll give you an example.

About six months ago I was talking to a network provider

and I said "can you give me some information about what we're talking about exactly?" So this network provider told me that -- let's take one particular procedure. Commercial insurance would pay \$135 for that procedure to that organization. Medicare would pay 85 for that procedure. Medicaid in Indiana would pay 25.

That is why it is hard for us to find physicians who are highly trained, who are knowledgeable, who understand all the things we've talked about this morning because of the reimbursement rate, because so many of our loved ones are on Medicaid because that's all we can get.

Fortunately some folks are able to access Medicare, which makes it a little easier for you to access provider care in the community.

So I think that in addition to what I would like to hear Liz come back next year and not only talk to us about what was passed, but then what are the specific rules and things that we all need to be aware of so as we advocate on behalf of ourselves or our loved ones or those in the community that we work with, that we can figure out a way to make this new system, whatever it is, work for us. But we're going to have to have good information in order to make it work.

[Applause.]

>> Steve: So Donna, I hear you reminding us, it was said earlier that in this enormous task of getting something passed, it's only going to be something. It's a beginning. And it is not going to answer all the questions. And it may not be the right direction, perhaps. But importantly the conversation won't end or the work won't end once we have some kind of legislation passed because then we got to go about the work of making it work, whatever it is.

Let's hear from Kim representing the Arc to hear her impressions or questions and continue the discussion.

>> KIM DODSON: Sure. I am very aware right now that I am the only thing standing between you and lunch, so I have kind of narrowed my comments to four points and kind of picked up a little bit what everybody said.

One, Steve has said something very important. We need to decide if we want something or if we want nothing. Personally, I think we are at a time where we need something done in healthcare. And, no, this is not going to be a perfect bill. Rarely when we talk about legislation and passing legislation, especially about an issue as complicated as healthcare, do we get it right the first time. But we have learned today that the issue is very complicated. And so we know that this is a critical issue facing so many of us, and so something needs to

be done now. And there is going to be a lot of discussion over the next few years of how to make it better and how to improve it. But the point is: We need to get something going now.

I want to talk real specifically for a second on the individual mandate option. You know, this is targeted primarily at the young and healthy. These are people who come out of college, think they are invincible, they are healthy, nothing is going to happen to them, they get a job and they deny their healthcare because they don't want to spend \$25 or \$100 a month on a healthcare premium that they don't foresee that they'll ever have to use.

Well, we know that on any given day at any given moment, we could be in a car accident. We could fall and break our leg. We could brush by somebody in a public mall and we are going to catch pneumonia. When this happens to people without healthcare insurance, they utilize the healthcare system in the most costly, inefficient way. So we need to make sure that these people, when offered health insurance, that they take up the health insurance because it's beneficial to all of us; it's to the public good.

Access to healthcare. Whether you live in Indianapolis, Evansville, Porter County, wherever, healthcare access is a huge issue. Transportation for people with disabilities is a huge

issue. And it's always going to be an issue until we get something done on transportation.

We need to look at how to deliver healthcare smarter. There are a lot of initiatives out there on telemedicine so that a specialist here in Indianapolis can help a family down in Evansville without that family in Evansville driving three hours up to Indianapolis. We need to utilize all of that more efficiently to deliver those services.

Julia talked a lot about the influence on special interests out in D.C. Absolutely. That is something that is going on. It is something that we cannot compete with. There are insurance companies spending millions of dollars every single day to buy somebody's vote.

But at the end of the day, they are accountable to us here in Indiana. All elected officials want to get reelected. Who votes? We vote. The PACs of the insurance companies, they do not vote. There is nothing more powerful in an election than an informed voter. You have to take it upon yourself to be an informed voter. If you have an opinion about healthcare, you must share your opinion with all elected officials. It is up to you, because you are the expert in how your health insurance -- or how your health is delivered to you. Nobody knows that better than you. You are the expert. You must share your story

with the elected officials.

So that is kind of the thing that if you have an opinion, it does no good to sit amongst a small group and complain about it. You need to talk to those people that can really make a difference, and that is our elected officials. They want to hear from you because they want your vote next November. So you need to get informed and you need to get active now.

[Applause.]

>> Steve: So that makes me wonder: What can we do? What's the thing we should leave here doing today? One question that you threw up here is what's the name of that book that Mr. Tilden brought up and that is called "Healing of america." by T. R. Reid. So we could read that and become informed.

But from the panel here, what would you charge this audience with doing? What should we leave here to do today to make sense of this and to move to the next level? What do you suggest?

>> NANCY JEWELL: Learn about the debates about the healthcare reform bill.

>> Steve: Become more knowledgeable.

>> And I would suggest to do what I'm doing with a group of young people Thursday night. We're meeting with our State Representative so that when these issues come to light, at least

he can put an issue with names and faces of young people that he has met.

>> SARAH STEIZNER: I would say understand what's in the bill that is beneficial to you all. I think our guest speaker did a fabulous job doing that.

I wanted to also mention that in terms of capacity Nancy was talking about, in terms of training physicians that understand all of these issues and understand the needs of families, one of the things that the AAP has been doing, the American Academy of Pediatrics, has been pleased with is it has language that includes the medical home. And I think that that really is important for you all. It came out of the American Academy of Pediatrics specifically for children and youth and families who have children and youth with special healthcare needs. And now it's really been taken up by internal medicine and all of the primary care specialties.

But I think that that is a positive that is in all of the bills. And so reimbursing for things that are included in a medical home that will be quite helpful for you all but also will make the practice of medicine more enjoyable for us, if we can spend the time doing the things that you all know and we all know are most important and get paid for it, that those things are going to happen a lot more frequently.

>> Steve: Thoughts over here about what we do?

>> JULIA VAUGHN: I would encourage you to find an organization that's involved in the debate. Maybe it's the Arc, maybe it's my group, Hoosiers for a Common Sense Health Plan, and get on a listserve so that you'll be getting regular updates. Things are going to really start moving fast once the Senate passes their bill. Make sure you know the details. And then communicate with our elected officials. I would say Senator Baye is going to continue to be a really important person in this debate. And he really, really needs to hear from us because he's getting the other side of the argument every day in Washington, D.C. He needs to hear from consumers.

>> Steve: So how many of you care about healthcare? Raise your hand or yell out loud.

(Yelling.)

And how many of you -- yes?

>> LIZ SAVAGE: I didn't mention. All of us in Washington are rude.

I think it's important to listen what's in the bills, but when I'll be lobbying and I'm walking around Senate offices, you have to hang out in the lobby and wait for the staff person. And you hear the receptionist answering the phone. They're getting so many calls on health care reform that you're not

going to have the opportunity to talk to a staff person. They're only going to want -- they don't really care. They don't have the time because they have so many calls on hold to talk to you about a specific provision. So you don't have to know the substance. The message is: Healthcare reform is important for people with disabilities. Support healthcare reform. And all they're going to ask you is your name and your Zip Code or your street or your town.

I guarantee you Senator Baye's receptionist is not going to ask you for your position on Section 856 or whatever the issue is. They just are keeping a running list of those constituents who are supporting healthcare reform and those who aren't. So it's really important for you to call his office, not only in Washington but around the state. And they keep track. And believe me, at the local offices as well as the Washington offices. And they feed all of those numbers into the Washington office. So it's really important. It's a numbers game right now from a grassroots perspective in terms of calls.

Emails. Staffers are so overloaded, they don't have time to read Emails. So it's important to say: Support healthcare reform. And for Senator Baye, support the CLASS Act.

>> Steve: How many of you care about this? How many have learned something important today about this healthcare reform

issue? How many of you are willing to continue the discussion and make calls and join groups to learn more? I didn't hear you, what?

(Loud yells.)

This is an issue that is extremely important to all of us. We've heard some very good information today that helps us better understand where we are. And you've got some great resources about where you can learn more and how we can partner together to make a difference. And it's critically important, I'm hearing, that our legislators know about how we feel, even if it's just to call and say: Make a difference. But I think you want to go beyond that, don't you? Yes. So you are charged with doing that.

At this point in the morning, we have to finish this session. We have a half an hour of time where you can continue talking to each other or any of these folks that can stay here, to visit the exhibit hall next door, to go take the survey and to make it downstairs in time by noon to enjoy lunch where we will have our awards ceremony and also a fabulous discussion about how you cash in on your creativity.

So at this time, please give a big applause and thank you to our presenters.

[CHEERS AND APPLAUSE]

And thank you for coming.

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